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An online self-care education program to support patients after total laryngectomy: feasibility and satisfaction

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Abstract

Purpose The purpose of this study was to investigate the feasibility of an online self-care education program supporting early rehabilitation of patients after total laryngectomy (TLPs) and factors associated with satisfaction.

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Methods Health care professionals (HCPs) were invited to participate and to recruit TLPs. TLPs were informed on the self-care education program “In Tune without Cords” (ITwC) after which they gained access. A study specific survey was used (at baseline T0 and postintervention T1) on TLPs’ uptake. Usage, satisfaction (general impression, willingness to use, user-friendliness, satisfaction with self-care advice and strategies, Net Promoter Score (NPS)), sociodemographic, and clinical factors were analyzed.

Results HCPs of 6 out of 9 centers (67 % uptake rate) agreed to participate and recruited TLPs. In total, 55 of 75 TLPs returned informed consent and the baseline T0 survey and were provided access to ITwC (73 % uptake rate). Thirty-eight of these 55 TLPs used ITwC and completed the T1 survey (69 % usage rate). Most (66 %) TLPs were satisfied (i.e., score ≥ 7 (scale 1–10) on 4 survey items) with the self-care education program (mean score 7.2, SD 1.1). NPS was positive (+5). Satisfaction with the self-care education program was significantly associated with (higher) educational level and health literacy skills ($P = .004$, $P = .038$, respectively). No significant association was found with gender, age, marital status, employment status, Internet use, Internet literacy, treatment modality, time since total laryngectomy, and quality of life.

Conclusion The online self-care education program ITwC supporting early rehabilitation was feasible in clinical practice. In general, TLPs were satisfied with the program.

Keywords Laryngeal cancer · Total laryngectomy · eHealth · Self-care

Abbreviations

HCP Health care professional
HNC Head and neck cancer
ITwC In tune without cords

TL Total laryngectomy
TLP Patient after total laryngectomy

Introduction

Laryngeal cancer is the second most common cancer of the upper aerodigestive tract [1]. Worldwide, it accounts for 130,000 new cases per year in men and 21,000 in women, with significant differences in incidence across countries [2]. In The Netherlands, ± 700 persons are diagnosed with laryngeal carcinoma annually [3]. Each year, about 150 Dutch patients undergo total laryngectomy (TL) [4].

A TL is performed in patients with advanced laryngeal cancer or in patients with recurrent disease after treatment with (chemo-)radiation. Patients who underwent TL (TLPs) face various physical and emotional challenges while returning home after surgery [5]. Changes in airway management, nasal function, swallowing and taste, loss of voice, neck and shoulder mobility problems, and impaired social functioning have a considerable impact on the quality of life of TLPs [6–9].

The provision of self-care education might be an effective strategy to adjust to these functional changes and to improve quality of life [10]. By providing access to clinician-generated self-care education via the Internet, patients can participate more effectively in their care and are supported in their information seeking [11–13]. The development and evaluation of tailored self-care education in a variety of forms, such as Internet and DVD, are urgently needed for patients who have undergone surgery for head and neck cancer (HNC) [14, 15].

To bridge the transition from hospital to home and to support self-management during rehabilitation after TL, an online program “In Tune without Cords” (ITwC) was developed, featuring a self-care education program and an exercise program. Both programs are provided with illustrated, tailored information and video demonstrations. To ensure that ITwC would adequately meet the needs of the end-users, a participatory design approach was followed, with stakeholders’ involvement in the development process [16, 17]. To guarantee the best utilization of the eHealth intervention, it is essential to be attentive to the usability, keeping in mind its intended users (e.g., clinicians, patients), task (e.g., medication management, self-management), and the environment (e.g., the outpatient clinic, at home) [18]. In a previous study on the usability of ITwC [19], TLPs and health care professionals (HCPs) evaluated content, completeness, and ease of use of a prototype of ITwC. Some technical revisions were made based on usability test results. However, usability of technology is determined not only by its user-computer interactions, but also by the degree to which it can be successfully integrated in the intended work environment [18]. Therefore, the aim of the present study was to investigate the feasibility of the self-care education program of ITwC in clinical practice by

assessing uptake and usage rate and user satisfaction of ITwC supplementary to regular care. Secondary aim of this study was to investigate which sociodemographic and clinical factors are associated with user satisfaction.

Methods

Study design

A single group cross-sectional study design was used, with a survey at baseline (sociodemographic and clinical information, Internet use, Internet literacy, health literacy, and quality of life) and a postintervention survey (usage, perceived satisfaction) 2 weeks after.

Patients and procedures

HCPs (a fellow head and neck surgery, specialized nurses or speech therapists) of nine departments of Otolaryngology-Head and Neck Surgery involved in laryngectomy care (represented in the Dutch Head and Neck Oncology Cooperative Group) [20] were invited to participate and recruit eligible patients for this study which took place between December 2013 and December 2014. Patients eligible for study participation met the following inclusion criteria: (1) recently underwent TL for laryngeal cancer; (2) underwent TL between 3 months to 2 years prior; (3) 18 years of age or older; (4) able to read, write, speak, and understand Dutch; (5) some Internet experience; and (6) access to the Internet at home. After receiving informed consent, patients were asked to fill out a paper-and-pencil survey (T0) and to return the survey by mail. Subsequently, login codes were provided to the patients by mail in order to gain access to the ITwC application for 2 weeks. In case of technical problems, telephone assistance was available. After 2 weeks of access, participants were encouraged by mail to fill out the second survey (T1). The study was conducted according to regular procedures of the local ethical committee of VU University Medical Center, Amsterdam.

Intervention

The self-management application ITwC [21] consists of a self-care education program and an exercise program. The education program provides general information about the larynx, laryngeal cancer, and the functional changes after TL. Specific self-care information is arranged into the following six themes: (1) nutrition; (2) tracheostomy care; (3) voice prosthesis care; (4) speech rehabilitation; (5) smell rehabilitation; and (6) mobility of head, neck, and shoulder muscles. The web pages on specific self-care contain self-care skills education (e.g., “How to use adhesive tracheostomy patches”), practical symptom management strategies (e.g., “What to do when

having taste problems”), and lists of troubleshooting guides targeting several symptoms (e.g., “Self-care strategies to overcome difficulty swallowing due to thick saliva”). Furthermore, ITwC consists of an exercise program with exercises for the head, neck, and shoulder muscles, aiming to prevent subsequent speech, swallowing, and shoulder problems after oncologic treatment. Self-care information, skills education, and exercises are illustrated with video animations, images, photos, and video demonstrations. Access to ITwC was restricted to study participants only via a login code. The present study focused on the online self-care education program. Therefore, participants had no access to the exercise program (see Fig. 1).

Outcome measures

A study-specific survey was composed comprising items on sociodemographic and clinical factors, a quality of life questionnaire, a health literacy scale (T0 baseline assessment), and on usage and satisfaction (T1 follow-up assessment).

Uptake, usage, and satisfaction

HCP uptake (the intention to refer) was defined as the percentage of HCPs that agreed to participate and were willing to

refer their patients to the education program of ITwC. TLP uptake (the intention to use ITwC) was defined as the percentage of all TLPs willing to participate (e.g., those who provided informed consent).

Self-reported usage addressed the percentage of active ITwC users (patients who logged in and visited ITwC during 2 weeks). Questions related to self-reported usage were asked the following: “Did you log in to the self-care program?”, “How much time did you spend visiting ITwC?”, and “Did you view the self-care skills demonstration videos?”

General satisfaction was based on the mean score of 4 items on (1) general impression of ITwC, (2) ease of use of ITwC, (3) willingness to use the ITwC program, and (4) satisfaction with ITwC self-care advice and strategies. All items were scored on a 10-point Likert scale ranging from “poor” or “low” (1) to “very good” or “high” (10). Furthermore, the Net Promoter Score (NPS) was calculated as an indication of satisfaction. The NPS is assessed by asking “On a scale from 0 to 10, how likely is it that you would recommend ITwC to other TLPs during the follow-up phase after TL?”. Responses were scored on a 10-point Likert scale ranging from “not likely” (0) to “very likely” (10). The NPS consists of the percentage of “Promoters” (those who score 9–10) minus the percentage of “Criticasters” (those who score 0–6). The NPS ranges

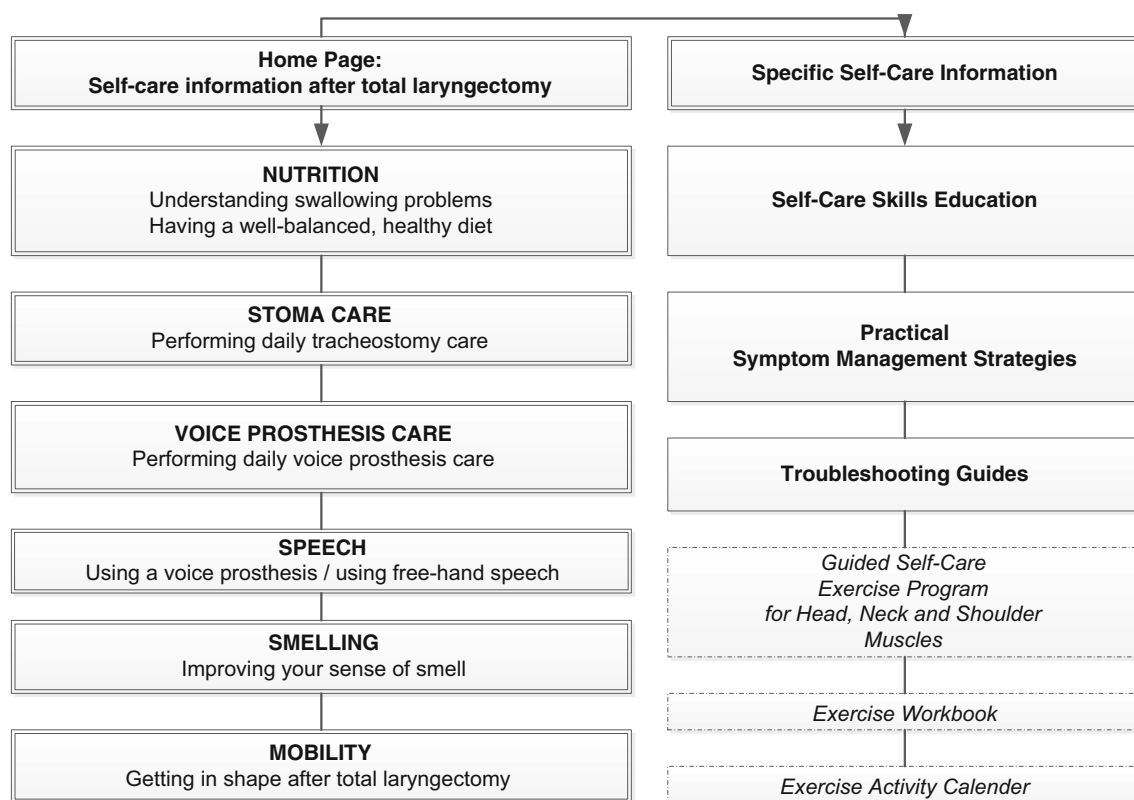


Fig. 1 Content of the ITwC application. The present study focused on feasibility of the online self-care program. Participants had no access to the exercise program

between −100 and +100 where a positive score is considered to be good [22].

The survey also included two open-ended questions: “How would you describe the ITwC self-care program to fellow users?” and “What could we do to improve the program?”

Moderating factors

Data were collected on gender, age, treatment modality, time since TL, education level, marital status, employment status, Internet usage, and Internet literacy, using a study-specific questionnaire. Education attainment level was categorized as primary education or less, low (lower and prevocational education), middle (secondary vocational education), and high (vocational college or university). Global quality of life was assessed using the EORTC QLQ-C30 (version 3.0), including a global Health Related Quality of Life (HRQOL) scale. In the present study, the global HRQOL scale was used. The scores of the QLQ-C30 are linearly transformed to a scale ranging from 0 to 100, with a higher score indicating a higher (i.e., more positive) level of HRQOL [23].

A Dutch translation of the Functional Communicative and Critical Health Literacy scale (FCCHL) by Ishikawa was used [24–26] to gain insight in TLPs’ health literacy skills (the capacity to obtain, process, and understand basic health information and services to make sound health decisions) [27]. The FCCHL-Dutch is based on the results of two validation studies in the Netherlands [24, 25] and consists of 14 statements with 4-point Likert scales (1–4). Mean scale scores were obtained by summing (reversed) item scores and dividing them by the total number of items, resulting in a score ranging from 1 (low health literacy) to 4 (high health literacy) [28].

Analyses

Descriptive analyses were used to summarize sociodemographic and clinical characteristics of TLPs as well as the uptake, usage, and satisfaction.

The self-care education program was considered feasible in case of (1) an uptake percentage by HCPs and TLPs of more than 50 %, (2) a user percentage of more than 50 % of the users visiting the ITwC Web site, (3) a user percentage of more than 50 % of the users viewing the demonstration videos, (4) in case of a positive Net Promoter Score, and (5) a mean general satisfaction score of at least 7 on 4 survey items. This definition of feasibility is based on adherence rates reported in previous research among head and neck cancer (HNC) patients who performed unsupervised, home-based exercises [29, 30].

Associations between satisfaction (score <7 vs score ≥7) with ITwC and gender (male vs female), education level (primary education/lower vocational education vs middle/higher vocational education), marital status (cohabiting vs single),

employment status (employed vs unemployed/retired), Internet literacy (insufficient/moderate vs sufficient/good/very good), Internet usage (<5 vs >5 years), treatment modality (TL as single modality treatment vs TL and (C)RT), and time since TL (recent TL vs 3 months to 2 years after TL) were examined using Fisher’s exact tests. Associations between satisfaction and age, quality of life, and health literacy skills were examined using Mann-Whitney *U* tests as these variables were not normally distributed. Analyses were performed using the Statistical Package for Social Sciences (IBM SPSS Statistics 20). For all analyses, *p* values $P \leq .05$ (two-tailed) were used as criterion for statistical significance.

Free text responses to two open-ended questions (TLPs’ description of ITwC to fellow users and TLPs’ recommendations to improve the ITwC program) were used as illustrations of quantitative data.

Results

Uptake

During the study period of 1 year, HCPs of 6 out of 9 centers agreed to participate, representing 5 academic and one nonacademic center(s), and recruited TLPs (HCP uptake rate of 67 %). Reasons for not participating were as follows: inability to get in contact with a HCP ($n=1$), inability to recruit TLPs ($n=1$), and other ongoing research projects ($n=1$). Of 92 eligible TLPs, 75 agreed to participate (82 %). Of the 17 TLPs who refused participation, 4 were not interested (3 TLPs who recently underwent TL (recent TLPs), and 1 TLP who underwent TL between 3 months and 2 years prior (later TLP)) and 13 TLPs had no time to participate (4 recent TLPs and 9 later TLPs). In total, 55 out of 75 TLPs who were willing to participate returned the T0 survey and were provided with a login code for the ITwC application (TLP uptake rate 73 %).

Usage

Among the 55 TLPs, 38 logged in and visited ITwC. The usage percentage was 69 %. Of these 38 users, mean age was 65 years, and the majority was male (76 %). Most were middle to higher educated (58 %), and most were treated with TL in combination with radiotherapy (61 %). Fifty percent was treated less than 3 months earlier. More details on the sociodemographic and clinical characteristics are provided in Table 1.

Table 2 shows TLPs’ self-reported usage of ITwC. Approximately half (55 %) spent less than 60 min using ITwC, 29 % spent 60–90 min, and 16 % spent more than 90 min during the study period of 2 weeks. The majority valued the time spent as exactly right (89 %), (strongly) agreed

Table 1 Characteristics of study participants ($n=38$)

Characteristic	Mean age, year (range)
Age	65 (46–78)
Gender	n (%)
Male	29 (76)
Female	9 (24)
Marital status	
Cohabiting	30 (79)
Single	8 (21)
Education	
Primary education	3 (8)
Low	13 (34)
Middle	12 (32)
High	10 (26)
Employment status	
Retired	17 (45)
Employed	12 (32)
Unemployed	9 (24)
Treatment	
Total laryngectomy	11 (29)
Total laryngectomy/radiation therapy	23 (61)
Total laryngectomy/chemoradiation	4 (10)
Time since total laryngectomy	
<3 months	19 (50)
3 months to 2 years	19 (50)
Internet usage since	
>5 years	26 (68)
<5 years	12 (32)
Self-assessed Internet literacy skills	
Very good	3 (8)
Good	7 (18)
Sufficient	12 (32)
Moderate	11 (29)
Insufficient	5 (13)
	Mean (SD)
Global quality of life (EORTC QLQ C-30)	75.0 (16.4)
Total health literacy scores (FCCHL-Dutch)	37.0 (9.0)

Low=lower and prevocational education

Middle=secondary vocational education

High=vocational college or university

that ITwC is beneficial in managing self-care (69 %), and reported no problems while performing self-care (89 %). Furthermore, demonstration videos were viewed by 84 % (32/38) of TLPs. One TLP (3 %) stated not being able to view the videos because of technical problems, two TLPs (5 %) reported not to know how to start the videos, and three TLPs (8 %) were not interested.

Table 2 TLPs' self-reported ITwC usage ($n=38$)

	n (%)
Time spent on "ITwC" during 2 weeks	
<60 min	21 (55)
60–90 min	11 (29)
>90 min	6 (16)
Time spent on "ITwC" was perceived as	
Too short	1 (3)
Exactly right	34 (89)
Too long	2 (5)
Much too long	1 (3)
To perform ITwC self-care strategies and advice is beneficial in managing my self-care	
Strongly disagree	0
Disagree	2 (5)
Neutral	10 (26)
Agree	23 (61)
Strongly agree	3 (8)
Any problems while performing self-care strategies and advice?	
No	34 (89)
Yes	4 (11)

Satisfaction

Of the 38 TLPs asked, 84 % were satisfied with the overall ITwC self-care program (mean score 7.4, SD 1.2), 74 % evaluated ITwC as user-friendly (mean score 7.3, SD 1.9), and 74 % of TLPs were enthusiastic about ITwC (mean score 7.0, SD 1.3). Most TLPs were satisfied with the specific self-care advice and strategies (79 %; mean score 7.1, SD 1.2). Overall, satisfaction was 66 % (average score of ≥ 7 (scale 1–10) on 4 items) with ITwC (mean average score 7.2, SD 1.1). The NPS was positive (+5), consisting of 25 % Promoters, and 20 % Criticasters.

Table 3 shows more details on TLPs' perceived satisfaction. The majority was (very) satisfied with the quantity (76 %) and comprehensibility (93 %) of the information provided in ITwC and did not need help using ITwC (82 %). Most would like to be introduced to ITwC before TL (37 %) or before hospital discharge (32 %). The majority of patients preferred the online format of ITwC (71 %), would like to continue using the Web site (87 %), and (strongly) agreed that photos and videos were of additional value (90 %).

Moderating factors

Satisfaction with ITwC was significantly associated with (higher) education level ($P=.004$) and (higher) health literacy skills ($P=.038$). Satisfaction with ITwC was not significantly associated with gender ($P=.46$), age ($P=.50$),

Table 3 TLPs' perceived satisfaction

	<i>n</i> %
The quantity of information is (<i>n</i> =38)	
Dissatisfactory	3 (8)
Neutral	6 (16)
Satisfactory	26 (68)
Very satisfactory	3 (8)
The comprehensibility of information is (<i>n</i> =38)	
Dissatisfactory	0
Neutral	3 (8)
Satisfactory	31 (82)
Very satisfactory	4 (11)
Needed help during ITwC visit? (<i>n</i> =38)	
No	31 (82)
Yes, I contacted the researcher or a HCP	7 (18)
Added value of ITwC to self-care advice offered during hospital stay? (<i>n</i> =38)	
Not at all	1 (3)
Little	20 (52)
Much	16 (42)
Very much	1 (3)
ITwC should be introduced (<i>n</i> =38)	
Before TL	14 (37)
After TL	3 (8)
Before hospital discharge	12 (32)
After hospital discharge	5 (13)
Other	4 (11)
Preferred format of ITwC (<i>n</i> =38)	
Online	27 (71)
Book	11 (29)
Prefer to continue to use ITwC (<i>n</i> =38)	
Yes	33 (87)
No	4 (11)
No response	1 (3)
Photos and videos are of added value (<i>n</i> =32)	
Disagree	0
Neutral	3 (9)
Agree	26 (81)
Strongly agree	3 (9)
Comprehensible information through photos and videos (<i>n</i> =32)	
Strongly disagree	0
Disagree	0
Neutral	0
Agree	30 (94)
Strongly agree	2 (6)

marital status ($P=1.00$), employment status ($P=1.00$), Internet literacy ($P=.10$), Internet usage ($P=.06$), treatment modality ($P=.46$), time since TL ($P=1.00$), and quality of life ($P=.75$).

User feedback and general recommendations

In general, TLPs reported to be satisfied with ITwC. One user mentioned specific self-care behavior changes, such as “After reading the troubleshooting guide I was able to manage some problems with my voice prosthesis on my own, and I did not have to contact the hospital.” Other users described the self-care education program as “a must,” “everything you always wanted to know,” “supportive information,” “a guide,” “very interesting,” “necessary information,” and “practical information.”

TLPs gave some helpful recommendations to improve the program. A section with “frequently asked questions” (FAQ) was recommended. Some TLPs would like to read other TLPs' experiences after TL. Suggestions were made to develop an application for a smartphone with links to an online store with tracheostomy products and accessories. A section with the latest news on tracheostomy filters, covers, adhesive patches, and (freehand) voice prostheses was also recommended. Furthermore, one TLP would like to have a help desk available to address any issues on work, relationship, sexuality, travelling, and general psychosocial aspects after TL. One TLP mentioned that he missed information on excessive flatulence, bloating, burping, edema, and on how to cope with and get support after TL.

Discussion

The aim of this study was to investigate the feasibility of an online self-care education program ITwC in terms of HCPs' and TLPs' uptake, TLPs' usage and satisfaction, and to identify factors associated with user satisfaction. Results revealed that implementing a self-care education program such as ITwC in a TL care setting is feasible both for HCPs and TLPs. In general, most participants were satisfied with ITwC.

HCPs' uptake rate (67 %) in our study is much higher compared to an earlier Dutch study evaluating an electronic health information support system for HNC patients, in which only 25 % of the general practitioners used the system [31]. Recently, it has become clear that by eliciting the viewpoints of clinical providers early in the process of developing new eHealth applications, eventual uptake can be improved [32, 33]. Expert-user involvement (HCPs) throughout all aspects of the development may have helped to ensure that ITwC adequately meets end-users' needs and is perceived to be easy to adopt [17]. The same holds for end-user involvement (TLPs) in ITwC design which may explain high TLPs' uptake rate of 73 % in the present study.

Among patients with HNC, acceptability of Internet-based programs is growing [34]. About 54 % of HNC patients use the Internet to find information about their treatment and on how to maintain their health in the future [35]. In the present

study, TLPs' usage rate of 69 % was somewhat higher compared to earlier studies on usage of eHealth interventions to provide support and education to HNC patients (55–64 %) [29, 31, 33]. It should be kept in mind, however, that in our study, patients were selected on having access to the Internet. Nevertheless, still, 29 % preferred to receive ITwC via a book format, while 71 % preferred the online version. Therefore, we also developed an ITwC book format, with a DVD with video animations, video demonstrations of self-care skills, and exercises. TLPs who are recruited in the multicenter randomized controlled trial are now either offered the online ITwC program or the ITwC book format with a DVD.

In the present study, satisfaction with the online self-care program ITwC was associated with a higher education level and with higher health literacy skills. These findings are consistent with the literature [36, 37]. Those with lower education levels are shown to be considerably less likely to seek for health information online compared to those with a higher educational level [38]. A lower subjective health literacy is associated with less perceived information provision and lower information satisfaction [39, 40]. To comprehend written health information, a person must have certain reading and health literacy levels [41]. HNC patients are known to have lower educational levels [42], have poor health literacy, have difficulties interpreting commonly used written health information, feeling inadequately informed. As a result, they feel dissatisfied with their care and with the information received [43]. Sites for HNC patients containing reliable information pitched at an appropriate reading level are rare, and the quality varies [44]. Visual cues and the use of alternative media may aid comprehension when people have difficulty understanding the text. In ITwC multimedia, self-care information (photos, video animations, and video demonstrations of self-care skills) was offered in addition to the written information, which may have contributed to high patient satisfaction [45]. By applying a participatory design approach, ITwC was designed to meet end user's needs, with information pitched at an appropriate reading level.

In the present study, some helpful recommendations to improve the ITwC program were made by end users. One TLP mentioned to miss information on specific self-care strategies. However, these guides and strategies were already provided for and may have been overlooked. Clearer navigation instructions were therefore added to the menu, and meaningful sub-headings were used.

A limitation of this study is that although various attempts were made to get in contact with interested TLPs by email or telephone, a number of TLPs ($n=17$) dropped out prior to completing the T1 survey. Results of this feasibility study are encouraging and support the initiation of a randomized controlled trial. A randomized controlled trial is now ongoing, aiming to investigate the efficacy of an online exercise program to support early rehabilitation of TLPs.

Conclusion

The online self-care education program ITwC supporting early rehabilitation was feasible among TLPs with access to the Internet. Satisfaction with the online self-care education program was associated with educational level and health literacy skills.

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Conflict of interest We have full control of all primary data, and we are ready to allow the journal to review data if requested.

No competing financial interests exist for either author.

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